## Members

Sen. Edward Charbonneau, Chairperson Sen. Randall Head Sen. Sue Errington Sen. Connie Sipes Rep. Vanessa Summers Rep. Dennis Tyler Rep. Cleo Duncan Rep. Phil Hinkle John Taylor



## INDIANA COMMISSION ON AUTISM

Legislative Services Agency 200 West Washington Street, Suite 301 Indianapolis, Indiana 46204-2789 Tel: (317) 233-0696 Fax: (317) 232-2554

## LSA Staff:

Hugh Beebe Dr. Gladys Beale

Dr. Robin Murphy

Francine Rowley-Lacy, Attorney for the Commission Chris Baker, Fiscal Analyst for the Commission

Authority: IC 12-11-7-2

## MEETING MINUTES<sup>1</sup>

Meeting Date: September 8, 2009

Meeting Time: 1:00 P.M.

Meeting Place: State House, 200 W. Washington

St., Room 233

Meeting City: Indianapolis, Indiana

Meeting Number: 1

Members Present: Sen. Edward Charbonneau, Chairperson; Sen. Randall Head;

Sen. Sue Errington; Sen. Connie Sipes; Rep. Vanessa Summers; Rep. Dennis Tyler; Rep. Cleo Duncan; Rep. Phil Hinkle; John Taylor; Dave Beck; Hugh Beebe; Dr. Gladys Beale;

Dr. Robin Murphy.

Members Absent: Michael Carmin.

Senator Charbonneau called the meeting to order at 1:07 p.m. Commission members introduced themselves and Francine Rowley-Lacy, Staff Attorney, read the Commission duties.

Peter Bisbecos, Director, Division of Disability and Rehabilitative Services (DDRS), presented a handout and discussed information concerning the service delivery system in

<sup>&</sup>lt;sup>1</sup> Exhibits and other materials referenced in these minutes can be inspected and copied in the Legislative Information Center in Room 230 of the State House in Indianapolis, Indiana. Requests for copies may be mailed to the Legislative Information Center, Legislative Services Agency, 200 West Washington Street, Indianapolis, IN 46204-2789. A fee of \$0.15 per page and mailing costs will be charged for copies. These minutes are also available on the Internet at the General Assembly homepage. The URL address of the General Assembly homepage is <a href="http://www.in.gov/legislative/">http://www.in.gov/legislative/</a>. No fee is charged for viewing, downloading, or printing minutes from the Internet.

Indiana for individuals with autism. (See Exhibit A) Information presented included the mission and vision of the DDRS, a summary of the guiding principles of DDRS, and the number of individuals with autism receiving services through the three Medicaid waivers for developmental disabilities, autism, and support services. The data was given according to age, gender, and regional districts in the state. Mr. Bisbecos stated that currently there are approximately 4,769 individuals with autism that are on the medicaid waiver list out of 20,461 individuals on the list for all three waivers. He presented information regarding the cost of services for individuals with autism and a comparison of services for individuals with autism and their families across the United States. He stated that twenty-five states are currently cutting services while Indiana is not. Ten states are expanding services, including Indiana. The Commission members asked Mr. Bisbecos to make a presentation at the next Commission meeting that includes specific information on services and funding for individuals with autism in the state of Indiana through the Family and Social Services Administration.

Dr. Cathy Pratt, Director, Indiana Resource Center for Autism (Center), gave a brief historical overview of the Center and discussed information contained in the Center's annual report for July 2008 to June 2009. (See Exhibit B). The Center engages in the following activities:

- (1) Conducts outreach training regarding positive behavior supports and evidence-based practices for teaching and supporting individuals with autism spectrum disorders across community, home, work and school settings;
- (2) Engages in individual consultations with the goal of facilitating an understanding of the issues, promoting collaboration among team members, and suggesting services and resources;
- (3) Trains and provides ongoing support to school teams to enhance programs and build local capacity to better educate individuals across the autism spectrum;
- (4) Conducts research that provides information to enhance quality programming for persons on the autism spectrum and that informs policy decisions:
- (5) Serves as a state clearinghouse for information about autism spectrum disorders by responding to individual requests for information, maintaining a library collection of relevant books and videos for public distribution, and monitoring current information on external resources, trends, policies, services, current treatments, and workshops;
- (6) Produces and disseminates information for professionals and families on autism spectrum disorders through newsletters, brochures, print, videotapes, and via the web; and
- (7) Evaluates materials and training to determine their impact and the need for change.

Dr. Pratt explained that this year the Center staff provided training and consultation services for 26,584 professionals, family members, and individuals on the autism spectrum. Dr. Pratt also presented a summary of the 2009 Indiana parent/family needs assessment survey. (See Exhibit C) She stated that 407 families participated in the survey and 88 counties were represented. She stated that as the number of individuals diagnosed with autism continues to increase, meeting the growing needs of those involved with individuals with autism presents a tremendous challenge. Today, according to Indiana's Child Count data (collected annually by the U.S. Department of Education, Office of Special Education Programs (OSEP) in accordance with Section 618 of Individual with

Disabilities Education Act (IDEA)) the incidence is 1 in 101. Areas of continued need include: early intervention, qualified personnel, employment opportunities, supported living options, and support for those who present behavioral challenges.

Dana Renay, Executive Director, Autism Society of Indiana, presented information concerning Indiana's comprehensive state plan (Plan) to guide services for individuals with autism spectrum disorders (ASD). (See Exhibit D) Ms. Renay gave a brief overview of the time line of when the Plan was developed and the goals of the plan. The Plan recognizes the following issues:

- (1) an insufficient recognition of the long-term effects on Indiana's medical and educational institutions, social services, and families;
- (2) under funded support services and training programs;
- (3) misinformation throughout the community about ASD; and
- (4) families who are forced to provide treatment and therapy on their own.

The Plan's recommendations include the following:

- (1) establishing an interagency ASD coordinating council or other entity to determine service gaps and establish benchmarks for achieving goals;
- (2) ensuring all individuals with ASD and their families will have a well established, trusting, and mutually respectful relationship with a healthcare professional who listens and responds to concerns, and who acts as an equal partner in providing a clearly defined plan of coordinated services;
- (3) establishing universal early identification of signs of ASD followed by appropriate referrals to a coordinated and comprehensive service system;
- (4) ensuring individuals and families with ASD have ready access to integrated and coordinated health, mental health, education and social services provided by well qualified ASD providers throughout their life cycle;
- (5) organizing community-based services so that individuals with ASD and their families can use them easily;
- (6) researching and developing best practices; and
- (7) increasing funding resources.

The Commission members asked Ms. Renay to distribute copies of the Plan to Commission members before the next Commission meeting and make a presentation at the next meeting that includes specific information on how the Plan is to be implemented.

Belinda Hughes, parent of an autistic child, testified that her husband's employer provided insurance does not cover services for autism spectrum disorders and inquired about the Indiana insurance mandate that requires coverage for autism related services for insurance plans from insurance companies based in Indiana and for state employee plans. Rep. Tyler informed her that IC 5-10-8-7.1 requires state employee insurance plans to cover autism related services and IC 27-8-14.2 requires any health or accident insurance policy that is issued in Indiana on a group basis to cover autism related services. Individual insurance plans must offer the option to include coverage for autism. He stated that there are a couple of exemptions for self-funded plans and for insurance companies that are not headquartered in Indiana. Senator Charbonneau asked that a representative from the Indiana Department of Insurance be invited to attend the next Commission meeting.

The meeting was adjourned at 3:00 p.m.